

GUIDANCE FOR SOCIAL NEEDS SCREENING AND DEMOGRAPHICS DATA COLLECTION

Sponsored by the MDPCP Program Management Office
at the Maryland Department of Health

Created by MedStar Health Research Institute

OVERVIEW

Purpose:

To provide practical guidance for MDPCP practices and Care Transformation Organizations (CTOs) seeking to implement or improve social needs screening and patient demographic data collection.

How was this toolkit developed?

The MedStar Health Research Institute developed this toolkit through a contract from the MDPCP program with funding from the National Initiative to Address COVID-19 Health Disparities Among Populations at High-Risk and Underserved, including Racial and Ethnic Minority Populations and Rural Communities. Our team includes implementation scientists, quality and safety researchers, human factors specialists, and primary care providers. We developed the toolkit through a multi-method approach: (1) interviews, focus groups, and surveys from MDPCP practices; (2) literature review; (3) consultation with subject matter experts.

Who should use this guide?

1. **Primary care practitioners** interested in learning about best practices in social needs screening and patient demographic data collection
2. **Clinical administrators or managers** interested in implementing practice-level change
3. **Individuals** interested in best practices to measure and promote health equity

How will you benefit from this guide?

This guide can help you:

- Understand how to choose social needs screening tools and patient demographic fields
- Scale screening according to the resource availability in your practice (e.g., size, informatics support)
- Customize demographics data review to advance health equity
- Access printable and online resources to support social needs screening and demographic data collection

The advice in this guide is supplemented by the following:



MDPCP Technical Assistance Resources Available: Technical Assistance is available to MDPCP practices through June 2023



Tips: Evidence-based suggestions and implementation advice



Tools and Resources: Data collection tools, user guides, and trainings

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MDPCP Technical Assistance Resources Available:

Our technical assistance team is available to provide one-time or ongoing, in-depth consultations to optimize clinical workflow and utilization of collected data to advance health equity. Have questions or want a consultation? Contact us at:

Email: MDPCP.socialneeds@medstar.net

Phone: 410-610-3893

INTRODUCTION

What do the terms Social Determinants of Health, Social Risk Factors, or Social Needs mean and why are they important?

Social determinants of health (SDOH) refer to the conditions in which people are born, grow, live, work, and age that affect health, functioning, and outcomes (World Health Organization). The five main SDOH domains include upstream factors like economic stability, education access and quality, neighborhood and built environment, social and community context, and health care access and quality.¹ It is estimated that clinical care, including access to care and quality of care, accounts for only 20% of health outcomes. Other factors, including social determinants of health (SDOH) and genetics and environment, explain 80% of health outcomes (Figure 1).

Social risk factors refer to the downstream impacts of the *structural* SDOH, or the ways that these structural factors and social conditions negatively impact individual health. However, patients with social risk factors may not *want* help to address a particular risk factor or may not see them as a priority. Thus, we define **social needs** as those social risk factors for which patients want to seek help. Examples of social needs include food insecurity, housing instability, or social isolation.

Patients with unmet social needs are at high risk of:^{2,3}

- Missing appointments
- Frequent emergency department visits
- Hospitalization and rehospitalization

Providing resources or tailoring care to consider identified needs could thus contribute to improving health outcomes.⁴



Figure 1. Factors contributing to health outcomes



Figure 2. Considerations in social needs screenings

Social Needs Screening trends from current MDPCP practices:

46% unsure about screening tool source

23% practices use their own tool

18% use the American Academy of Family Physicians tool

14% use PRAPARE

2% use the Accountable Health Communities tool

** Based on data collected May-June 2022 about current workflows and needs of MDPCP practices, including 61 survey responses, 20 interviews, and 1 focus group.*

Our survey found that the most common needs cited by MDPCP patients were:

84% – Transportation

51% – Food insecurity

43% – Paying for utilities

41% – Housing instability

18% – Employment

Most practices already collect demographic data such as age, ethnicity, and race. However, this information is rarely collected in a standardized manner. Further, practices may not have the infrastructure or resources to analyze demographic data to assess disparities in care or care outcomes.

Collecting data on social needs screening is a key step towards achieving equity and providing quality health care. Primary care practices can serve as a bridge between patients who need help in meeting essential social needs and community-based organizations who are able to meet these needs.

Note: Screening your patients for social needs does not mean that your practice is expected to address all social needs. Rather, screening and referring for social needs should be similar to how

“We can’t assume because someone outwardly appears like they’re okay and that they have everything they need, that they actually have everything they need.”

–MDPCP PRACTICE SUPERVISOR

you approach specialist referrals. Just like how you would refer your patient to an orthopedic surgeon for their broken hip, you might refer your patient to a social worker or use a database such as [211 or findhelp.org](https://www.211.org/) to connect the patient with a food pantry if they are experiencing food insecurity.



What do we mean by detailed demographic data and why is it important?

Asking patients about their social identity creates an opportunity for the patient to share more about their lived experiences and how it impacts their health. Most practices already collect data on demographics such as age, ethnicity, and race. However, demographic information is rarely collected in a standardized way. Further, many practices do not have the infrastructure or resources to analyze data to assess disparities in care or outcomes. However, collecting detailed demographic information about ethnicity, race, language preference, disability, sexual orientation, gender identity, or other factors can better allow practices to understand the need for targeted educational materials, track quality indicators, and address challenges faced by marginalized populations.

Collecting patient demographic data can help practices:

- Create targeted educational materials and quality improvement interventions to promote health equity
- Assess whether the practice is delivering culturally competent care
- Develop additional patient-centered services
- Identify whether health disparities exist for specific patient populations

Screening for social needs and collecting demographic data helps in:²⁻⁴

- Choosing treatment plans tailored to personalized patient needs and priorities
- Improving patient adherence to treatment
- Delivering value-based care
- Improved patient and provider satisfaction with care
- Achieving clinical outcomes critical for value-based payment and MDPCP care transformation requirements



This short [module from the AMA](#) includes example case studies of why demographic data is important to collect.

SOCIAL NEEDS SCREENING

Key Implementation Steps

Step 1. Decide which screening tools and questions will contribute towards advancing health equity within your practice

Previous real-world implementation of social needs screening has suggested that most clinics think they are screening far more individuals than they are in practice. Thus, we encourage all practices to review current social needs screening processes and reflect on the following questions:

1. Which social needs are most prevalent in the patient population you serve?
2. How would you describe your team's current practice for data collection?
3. Are the social needs you want to assess and address measured by existing screening processes?
4. Are you using validated or commonly utilized questions?
5. What gaps do you see in your team's education and training around collecting social needs?

6. How does your practice review collected social needs data to improve patient care?
7. If your screener is outside the EHR, what possibilities are there for working towards electronic collection and review of information?
8. How can your team's processes be strengthened?
9. If you could implement any process around social needs screening and review of data, what would it look like?

Advantages of using an established social needs tool include:

- Comparability with other clinics or populations
- Confidence that interdisciplinary experts have included key factors related to health
- User testing to improve how questions are worded and understood

Example tools such as the [Accountable Health Communities](#), [Health Leads](#), and [American Academy of Family Physicians](#) are commonly used and well tested. Brief descriptions of each can be found below.

Accountable Health Communities Tool

This ten-question tool covers housing instability, food insecurity, transportation difficulties, utility assistance needs, and interpersonal safety, among others. It is endorsed by the Center for Medicare and Medicaid Services.

American Academy of Family Physicians Tool

This tool is an eleven-question provider short-form and is also offered in Spanish. It can be administered by clinical or nonclinical staff or self-administered by patients. This tool covers housing, food, transportation, utilities, personal safety, and assistance.

Health Leads Tool

This tool is built for patient populations with low health literacy. Containing graphics and written at a 6th grade reading level, this tool is also offered in Spanish and covers economic stability, education, social and community context, neighborhood and physical environment, and food.



If you are considering adopting new questions or a new screener, an excellent resource to further compare social needs questionnaires by length, domain, intended population, and other key factors like health literacy is hosted [here](#).



MDPCP Technical Assistance Resources Available: Our team can help review your practice priorities and help select a tool or specific questions to meet the needs of your patient population and workflow constraints.

Your staff may also choose to document social needs through ICD-10 codes.

Table 1. Example social needs and associated z-codes

Social needs questions	Z-code	Description
Paying for basics	Z59.9	Economic circumstances affecting care
Worried about food running out	Z59.41	Food insecurity
Unable to pay rent with risk of eviction	Z59.811	Housing instability
Transportation	Z59.89	Inability to acquire transportation



Tool: Z-codes are ICD-10 codes used to document patient data on social needs (housing, food insecurity, transportation, etc.) in a discrete and standard manner in a patient's chart. Z-codes may improve claim accuracy and specificity, and support the case for reimbursement. Codes are in the range Z55-Z65 (See examples in Table 1). The American Hospital Association provides coding guidance for ICD-10-CM code categories related to social needs.

Step 2. Consider how you will fit the Social Needs Screening within the clinical workflow.

How should you collect social needs data?

There is no single or “correct” way of collecting social needs. **The best way to collect social needs is what works best for your practice.**

MDPCP survey respondents were asked who the most appropriate person is to ask social needs questions.

There was a slight preference for care managers (25%), followed by advanced practice providers (21%), medical assistants (21%), forms filled out by the patient at check-in (18%), and the patient portal (5%).

Practices cited top barriers to using social needs screening questions as: Not enough time (48%), Conversations need to happen naturally (46%), and not knowing where to refer patients if a need is identified (30%).

These cited barriers of time, [limited referral capacity](#), and [training](#) on how to ask these sensitive questions are discussed throughout the toolkit, and can be addressed individually with practices through MDPCP technical assistance.

[Figure 3](#) details a user guide employing key questions to consider when choosing a social needs screening workflow. The summary score may be used as a guide to help you adapt an existing workflow or select a new process. [Table 2](#) presents examples of Informatics and workflow considerations, with attention to potential MDPCP technical assistance options.



Tip: Do you have a practice “champion” who has driven previous practice change? Previous implementation projects suggest the importance of this role in successful implementation of new workflows.

Figure 3. Selecting a screening workflow

User guide to selecting a screening workflow

Please answer the questions below to the best of your ability.

In your practice, is it more important to capture a wide variety of social needs or a select few based on practice priorities?

A wide variety of questions (1)

It depends on workflow factors like time and staffing (2)

A select few social needs based on practice priorities (3)

Does your practice prefer collecting data using paper forms or tablets, the Electronic Health Record, or both?

Paper forms/tablets (1)

Both (2)

Electronic Health Record (3)

Do you have staff members who have the time and skills to transcribe information on paper to the EHR?

Yes (1)

Sometimes (2)

No (3)

Does your staff have training or otherwise feel comfortable discussing difficult subject matters with patients?

No (1)

Sometimes (2)

Yes (3)

Do you have the time within your workflow to discuss social needs with patients and engage them in conversation if need be?

No (1)

Sometimes (2)

Yes (3)

Does your patient population have primarily high, moderate, or low health literacy?

High (1)

Moderate (2)

Low (3)

Please count the number of points you've selected as indicated by the numbers in parenthesis.

If you've scored between **6-10 points** your practice might be best suited to a patient-administered workflow

If you've scored between **11-13 points**, your practice might be best suited to a hybrid workflow

If you've scored between **14-18 points**, your practice might be best suited to a clinician-administered workflow

Table 2. Example Informatics Workflows related to Social Needs Screening

Workflow Type	Level of Effort/Cost	Requirements	Sample Tools	Integration into Workflow	Example MDPCP Technical Assistance
MDPCP PMO recommends digital capture for social needs screening responses that allow for embedded integration to the EHR. All other informatics workflows should be considered options.					
Tablet Based EHR Embedded Screener	High/\$\$\$\$\$	Web/mobile app developers and EHR vendor support	Custom built iPad/ Tablet and EHR applications	Provider not required to leave normal workflow	Assessment of integration options, advising on developer for custom Tablet application, options for EHR integration
Staff administered in EHR	Medium/\$\$\$	Development of an embedded EHR data entry	EHR dependent custom data entry screen	Provider not required to leave normal workflow	Advising on EHR data entry screen options
Patient Portal Screener	Medium/\$\$	Integration of new data source into EHR	Patient portal integration of additional data elements into the EHR	Provider not required to leave normal workflow	Facilitation of site readiness for additional integration of screener data capture
Staff administered in CRISP	Medium/\$\$	Integration into the CRISP Health Information Exchange	CRISP Integration into EHR or use of CRISP portal	Depends whether component/ module integrated into the EHR or if provider must log into CRISP Portal	Facilitation of site readiness for CRISP integration
Tablet Based External Screener (3rd party non-EHR tool)	Medium/\$\$\$\$	Web/ mobile app developers	iPad/Tablet + REDcap, Tonic, etc.	Provider must log into an external system to view	Advising on developer for custom Tablet and external site for viewing responses
Patient Completed Paper Forms	Low/\$	No technical development	None required	Provider must review paper forms, or staff can enter paper forms into EHR	Support in development content for paper forms

Example decisions around social needs domains and workflow based on practice needs:

A practice has decided to use a paper screener due to concerns around EHR modifications and the lack of time or appropriate person to conduct and review the screening with the patient. Since the provider does not plan to discuss screener findings with the patient directly, you determine that asking additional questions on the paper screener beyond those that you have resources identified for would cause more harm than good. You select the two top needs commonly described by your patients and offer printed handouts at checkout from the front desk for those who screen positive on those two needs.

A practice determines that it is important for someone on the medical team to initiate the discussion with patients in order to elicit truthful responses and to build trust between the patient and provider. There is a social worker or other team member who can follow up with the patient on identified issues. You include an electronic screener during the clinical visit. While you only can provide referrals to community organizations for food insecurity and transportation, you opt to ask about other domains such as housing in order to provide contextual care, destigmatize discussion of these concerns and how they might affect health, and to build the patient-provider relationship.

While paper screeners may help identify needs on the level of each individual patient, electronic data collection offers the following additional benefits:

- Ability to create systems to review aggregate data (e.g. dashboard, quarterly reports)
- Potential for data sharing as appropriate (e.g., Chesapeake Regional Information System for our Patients (CRISP), or other facilities within your healthcare network and EHR) so that the patient does not have to be asked sensitive questions multiple times
- Real-time access to completed forms available to address patient needs during clinical visits.



Tip: Mailing screeners should be sent and interpreted with caution. Sending a social needs screening questionnaire by mail may result in a biased response. Those with lower health literacy or those who fear disclosing personal information by mail may be less likely to respond. Any mailed screeners should carefully detail who is collecting the information and what will be done with it. Also, a plan should be in place to determine what to do with the completed surveys.

After workflows are in place, it is important to avoid unnecessary screening. For instance, a patient returning for a follow-up a week after an initial visit does not need to be re-screened. While there is no gold standard for frequency of screening, some experts suggest **annual** screening, and where administered electronically, offering patients the option to opt-out of future screenings.

When MDPCP practices were asked how often they ask patients about social needs, about half of respondents (49%) reported having conversations with patients annually, and 46% reported having conversations whenever it comes up or that it was dependent on the patient.



"I hate asking uncomfortable questions that I can't fix."

—NURSE CARE MANAGER



Step 3. Determine how you will use Social Needs Screening information

What should you do with identified social needs?

Providers often mention that they hesitate to ask questions if they cannot address the need. Note that even if you cannot address a need, asking about social circumstances in conversation may have benefits. These conversations can strengthen patient-provider relationships, destigmatize social services, and increase the focus on social investment by acknowledging the impact that societal factors have on individual health.⁵


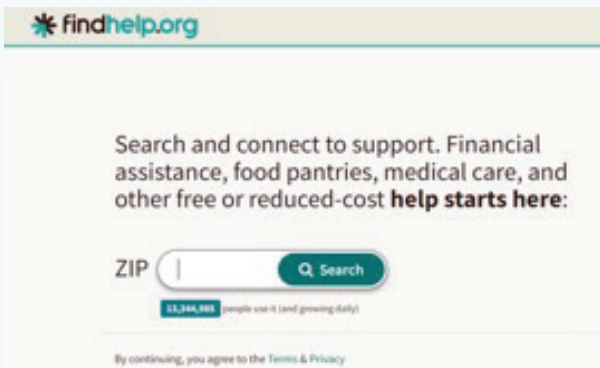



Tip: Screening may identify a social need, but patients may not want help. It is important to sensitively ask the patient whether he or she wants help for the mentioned need. You can find an example of this in the [AAFP tool](#).



Tool: Some practices may include a social worker or community health worker to provide help and resources to patients. However, even without specialized staff, there are other resources available to help you set up a workflow at your practices to efficiently provide community referrals. The resources in [Table 3](#) can be used to help identify resources and social services available for patients within the state of Maryland.

Table 3. Publicly-available databases for social service referrals

211 Maryland	
<p>Patient-relevant services:</p> <ul style="list-style-type: none"> Housing Family crisis Financial assistance Legal assistance Employment Other services <p>How to use resource (4 options):</p> <ul style="list-style-type: none"> Navigate to https://211md.org/ Dial 2-1-1 to connect with regional call center Text zip code to 898-211 or chat online with 211 specialists using https://211md.org/ Sign up for push alerts by texting a keyword to 898-211 <p>This might be helpful if:</p> <ul style="list-style-type: none"> A patient does not have access to internet A patient prefers text communications for alerts and updates 	 <p>211 Mental Health Resources: 211 Health Check: Sign up for weekly mental health check-ins by dialing 211 and pressing 1 for Health Check (or text HealthCheck to 211-MD1) 211, Press 1: Provides confidential mental health services and substance use services in times of crisis https://211md.org/resources/mental-health/</p>
Findhelp.org	
<p>Patient-relevant services:</p> <ul style="list-style-type: none"> Food Transportation Housing Health care Employment Financial assistance Other free and reduced cost services <p>Practice-relevant services:</p> <ul style="list-style-type: none"> Streamline workflows Communicate with team members Track referrals <p>How to use resource:</p> <ul style="list-style-type: none"> Navigate to https://findhelp.org Enter zip code in which help is desired <p>This might be helpful if:</p> <ul style="list-style-type: none"> You need help finding the best resources for patients within a zip code that is not familiar to you You need to filter programs based on age, language, disability, etc. 	 <p>This might not be helpful if:</p> <ul style="list-style-type: none"> You have social workers or Community Health Workers (CHWs) who already have direct connections to resources
Additional Resources:	
<p>MDPCP also maintains a resource directory of locally relevant tools related to Behavioral Health, Social needs, and other services.</p> <p>A new 24/7, free and confidential national suicide and crisis hotline was created to provide immediate resources to those in crisis. You can call or text 988, or can chat online at www.988lifeline.org. There are also key messages and a partner toolkit available that providers may want to reference for more information.</p>	

Ways to present resources to patients:

- Provide printed handouts in hanging folders in exam rooms
- Have a tablet available in waiting room or exam room
- Keep a board in office with small rip off tabs for patients to take

Ways to enhance communication about resources:

- Create an online resources binder at your practice
- Create a google chat between staff to share common resources
- Discuss new resources at weekly or monthly meetings

In interviews and surveys, MDPCP practices reported the above example practices for addressing identified needs.


Nearly half of MDPCP practices responding to surveys reported documentation in free text about referrals, while 15% reported documenting in a structured field.

Those who do not document referrals may consider which options might work best in their clinics

and if desired, can work with MDPCP technical assistance about how this information can be tracked.

Step 4. Train your team to ask about social needs in a sensitive and culturally competent manner

Because many of these questions are sensitive, it is important to consider how questions should be asked. Studies suggest that provider training on social care leads to increased provider confidence, positive feedback on workflow changes including screening taking less time than anticipated, and decreased concerns about patient discomfort, with no negative impact on the relationship with patients.⁶



Tip: Patients may be wary of being profiled because of the nature of questions. These concerns can be addressed by implementing universal screening (i.e., screening every patient), and communicating the policy of universal screening to all patients. In [Table 4](#) please find example language to introduce a screener.

Table 4. Scripting options to consider

Principle	Example language for a provider-administered screener	Example language for a self-administered screener
Support autonomy and respect privacy	“Is it ok if we spend a few minutes talking about your experiences and priorities in your life outside the clinic that might be affecting your health? I want to acknowledge that some of the questions might feel kind of sensitive, so please feel free to let me know if, at any time, you don’t want to answer any of these questions.”	“We would appreciate it if you would answer the following questions. If you would prefer not to answer these questions, that is fine.”
Provide a clear explanation for conducting the screening, how information will be used, and options for follow up	“We are having these conversations with all of our patients so that we can understand better what might be affecting your health and well-being. We may be able to help you get connected to resources, though we can’t guarantee that will be the case. Even where we can’t connect you to assistance, this information will help us partner with you to create a care plan that fits your life. Understanding what the patients we serve are experiencing also helps us to be a better advocate for our community.”	“At preventative visits we ask everyone to complete a variety of questionnaires. Our goal is to identify your needs and concerns so that we can best determine how we might contribute to improving your health. Some of these questions may be sensitive- we encourage you to answer as honestly as possible. After you complete the forms they will be shared with your provider. If you have any questions or concerns please address them with the provider during your visit.”
Ask about patient priorities	“I looked over the questionnaire you filled out and I see that you are experiencing some difficulties with X, Y and Z. What are your top priorities here? What makes these feel important to you?”	“Would you like help with any of these things you mentioned?”



Tool: You may browse additional language to introduce screeners [here](#).



Tool: You may want to add some [printouts](#) in exam rooms to normalize these discussions at your practice.

Culturally competent care is critical to the success of collecting sensitive information such as social needs. While asking these questions can support advancement towards health equity, if individuals do not have proper training on cultural competency, asking these sensitive questions could negatively impact patient care and health, undermining the goals of such questions.

Resources for how to ask social needs questions and understand culturally and linguistically appropriate services:

- A [description of empathic inquiry](#) from the Oregon Primary Care Association with various tools and videos
- A [SDOH conversation guide](#) from the Oregon Primary Care Association
- The Office of Minority Health Resources hosts a [page on cultural competency](#) including information, continuing education opportunities, and resources focused on culturally and linguistically appropriate services (CLAS) to advance health equity and improve quality of care

DEMOGRAPHIC DATA COLLECTION

Key Implementation Steps

Step 1. Decide which demographic questions will contribute towards advancing health equity within your practice

Leading professional societies and federal agencies have undertaken in-depth studies in recent years to review existing required demographics and how they should be asked. Including detailed demographics provides insight into disparities in outcomes, resources that might be most culturally appropriate, and may align more closely with how patients self-identify. MDPCP practices responding to surveys reported collection of the demographics shown below.

The percentage of MDPCP practices that reported collecting the following demographic fields:

93%–Race

88%–Ethnicity

59%–Gender identity

42%–Sexual orientation

41%–Sex assigned at birth

We encourage all practices to review and reflect on the following questions about demographic data collection:

1. Do you provide patients with information on why collecting demographics are important before asking their responses?
2. Do patients self-report their demographics?
3. What gaps are there in training for providers? Do they have scripts on how to ask patients about their social identity?
4. Is there a standardized process for collecting demographics in the EHR?
5. How can the existing practice processes improve?

We seek to address these questions in the following sections.

Some demographics to consider include those in the [ADDRESSING](#) Framework, such as:

- Age
- Disability
- Religion
- Ethnicity
- Race
- Socioeconomic status
- Sexual orientation
- Gender Identity
- Pronouns
- Indigenous heritage
- National origin

Table 5 below presents some expanded demographic fields that have been developed by expert consensus.

Table 5. Example demographic fields with citation to how they were developed

Questions you can use at your practice to accurately capture sexual orientation, gender identity, and pronouns ⁷		
Domain	Question	Response
Sex assigned at birth	What sex were you assigned at birth, on your original birth certificate?	Male Female Intersex <hr/> Prefer not to say
Sexual Orientation	Which of the following best represents how you think of yourself?	Lesbian, Gay, Homosexual Straight, Heterosexual Bisexual If respondent is American Indian and Alaska Native (AIAN): Two-spirit <hr/> Prefer not to say
Gender Identity	What is your current gender?	Man Woman Nonbinary/Gender Fluid Trans Man Trans Woman If respondent is AIAN: Two-spirit Prefer to self-describe <hr/> Prefer not to say
Pronouns	What pronouns do you use?	Male/masculine: he/him/his Female/feminine: she/her/hers Gender neutral: they/them/their Gender neutral: ze/hir/hir
Suggested expanded categories for ethnicity to consider for your practice		
Question	Minimum OMB categories	Expanded OMB categories
Are you Hispanic, Latino/a, or Spanish Origin? (One or more categories can be selected)	Not of Hispanic, Latino/a, or Spanish origin	Not of Hispanic, Latino/a, or Spanish origin
	Hispanic, Latino/a, or Spanish origin	Mexican, Mexican American, Chicano/a Puerto Rican Cuban Another Hispanic, Latino/a or Spanish origin



Tip: Key considerations in demographic data collection

- Do not assume that a patient has a certain social identity, asking the question allows the individual the opportunity to self-identify
- Ordering of response options can affect how respondents answer. Consider alphabetic ordering of response options so that it does not appear that there is hierarchy or preferred answer
- When race and ethnicity are collected separately, ethnicity should be collected first⁸
- Participants who wish to identify their multi-racial heritage should be allowed to select more than one race, rather than using a “multiracial” category⁸
- Respondents should be able to opt out of sexual orientation or other identity questions if they fear that disclosure could have negative repercussions

Suggested expanded categories for race and nationality to consider for your practice		
Question	Minimum OMB categories	Expanded OMB categories
<p>What is your race? (One or more categories can be selected)</p> <p>For additional race categories to choose from, use the CDC/HL7 Race and Ethnicity Code Set 1.0.</p>	American Indian or Alaska Native	American Indian or Alaska Native
	Asian	Asian Indian Chinese Filipino Japanese Korean Vietnamese Pakistan Thai
	Black or African American	Black/African American African Botswanan Ethiopian Liberian Namibian Nigerian Haitian Jamaican
	Native Hawaiian or Other Pacific Islander	Native Hawaiian Guamanian or Chamorro Samoan Other Pacific Islander
	White	European Armenian English French German Irish Italian Polish Scottish
Validated questions for language to consider at your practice ⁸		
Domain	Question	Response categories
Primary Language	How well do you speak English? (select one)	Very well Well Not Well Not at all Prefer not to say
Spoken Language	Do you speak a language other than English at home?	Yes No Prefer not to say
	If yes, which language?	_____
Interpreter	Do you generally need an interpreter to communicate?	Yes No Prefer not to say

In prioritizing fields to collect, it is also important to think about how detailed demographic data will inform clinical care. Practices may want to assess outcomes or quality measures by ethnicity, race, disability, income, or other characteristics to target resources to support those individuals in improving health outcomes.



MDPCP Technical Assistance Resources Available: Our technical assistance team can help with selection of specific fields to add, or methods for better tracking and reviewing data that is already collected.

Step 2. Consider how you will collect Demographic Data within the clinical workflow

Similar to collecting information about social needs, there is no single workflow option for collecting demographic data.

When asked about the challenges in collecting demographics, participants indicated there was not enough staff (36%), not enough time (35%) or that individuals were uncomfortable asking certain questions (21%).

Workflows thus may be selected to address barriers related to staffing and time, or provider/patient comfort.

Patient demographics can be collected by the following options:

1. Patient portals
2. Registration forms completed prior to an appointment
3. Providers and the care team can discuss demographics as part of social history
Example: A provider can begin by introducing their own pronouns—“My name is Dr. Smith. My pronouns are he/him. How would you like to be addressed?” Providers may also choose to add their pronouns to a name tag to invite conversation.



Tip: Regardless of the workflow you choose, we recommend pilot testing your workflow in a subset of your practice (e.g. 1-2 providers) or for a limited time before full-scale launch and determine metrics of measuring successful implementation. You may find some helpful tools from the Agency for Healthcare Research and Quality [here](#) for planning a new process at your practice

Similar to social needs, patients should be given the option to update their demographics annually.

Step 3. Determine how you will use Demographic Data

Patient demographics can be used to provide connection and build trust with a patient, allowing a patient to feel seen or share more personal elements of factors affecting their health.

In the MDPCP survey, participants reported that demographics were most commonly used to connect with patients (44%) or for aggregate reporting data (42%).

In addition to informing individual care, demographics can also be used for:

- Planning for language assistance services to support clinical staff
- Development of health promotion outreach materials to sub-populations who are high healthcare users
- Identifying differences in health status, quality of care, and outcomes by population characteristics



MDPCP Technical Assistance Resources Available: The MDPCP technical assistance team can work with you to create a pilot test and metrics of success for any process changes or analysis of your patient data.

The **Plan-Do-Study-Act (PDSA) cycle** (see Table 6) is a useful tool for documenting a test of change. Running a PDSA cycle is another way of testing a change — you develop a plan to test the change (Plan), carry out the test (Do), observe, analyze, and learn from the test (Study), and determine what modifications, if any, to make for the next cycle (Act). We provide an example of how this can be applied to new data collection processes in Table 6:

Table 6: Example Technical Assistance in Using Demographic Data to achieve health equity

In-depth, ongoing consultation strategy (incorporating PDSA cycle)	Single consultation
<p>Plan: Work with MDPCP technical assistance team to consider whether additional data collection fields are needed</p> <p>Plan: Practice develops workflow with planning input from MDPCP technical assistance team as desired</p> <p>Plan: MDPCP technical assistance provides relevant training resources on collecting and analyzing detailed demographics</p> <p>Do: New data collection and feedback loop processes launch</p> <p>Study: MDPCP technical assistance team provides audit and monitoring protocol (accommodating limited EHR capabilities)</p> <p>Study: Findings discussed at learning health collaborative if feedback is desired</p> <p>Act: MDPCP technical assistance team provides print resources relevant to findings to address any identified needs specific to language-specific sub-populations</p>	<p>MDPCP technical assistance team helps identify relevant data collection fields and provides customized checklists to meet practice-specific needs and capabilities for pilot testing and launch</p> <p>MDPCP provides ongoing resources as desired/requested by the practice</p>



MDPCP Technical Assistance Resources Available: Our team can work with your practice on creating a PDSA cycle that fits with your workflow and objectives.

Step 4. Train your team to ask about demographic questions in a sensitive and culturally competent manner

Similar to social needs questions, many of these questions are sensitive, and it is thus important to consider how questions should be asked. Below we describe principles for demographic data collection (Table 7), as well as publicly available trainings.

Table 7. Guiding principles for demographic data collection⁸

Principle	Explanation
Inclusiveness: People deserve to count and be counted	Everyone should be able to see themselves, and their identities, represented in surveys and other data collection instruments. Not asking a question suggests that we are assuming we know how an individual identifies.
Precision: Use precise terminology that reflects the constructs of interest	Sex, gender, and sexual orientation are complex and multidimensional. Questions should clearly specify which component(s) of sex, gender, and sexual orientation are being measured, and one construct should not be used as a proxy for another. See a provider printout distinguishing these terms here .
Autonomy: Respect identity and autonomy	Data collection must allow respondents to self-identify whenever possible, and any proxy reporting should reflect what is known about how a person self-identifies. All data collection activities require well-informed consent from potential respondents, with no penalty for those who opt out of sharing personal information about themselves or other household members.



Tool: The following resources are publicly available and may be useful to team members beginning this learning journey or those who want to revisit suggestions for how sensitive questions should be asked.

- Training materials for asking about sexual orientation and gender identity from [Whitman Walker](#); includes videos, role play examples, and print outs

Training on demographics:

- The Health Research and Educational Trust organization, with the American Heart Association, created a [short powerpoint](#) on collecting race, ethnicity, and primary language
- GMLA is a national organization dedicated to advancing LGBTQ equality. They offer a series of webinars on quality healthcare for LGBTQ individuals including how to create comprehensive systems of care. [Training on LGBTQ sensitivity](#)
- Whitman Walker is a community-based healthcare organization dedicated to advancing social justice and equality through healthcare. They developed a culturally competency tool that offers case scenarios, information, and considerations for asking sensitive demographic data <https://culturalcompetency.org/>

Trainings for CME:

- [Collecting Patient Data: Improving Health Equity in Your Practice](#); Interactive course, 0.75 CME credits, includes additional resources
- [How to collect Accurate and Complete Race / Ethnicity Data – A Step Toward Improving Health Equity](#); Webinar/ video, 60 minutes, 1.00 CME credits
- [Narratives and Language](#); Audio, 48 minutes, 0.75 CME credits (can be downloaded)
- [Implicit bias](#), a 45-60 minute training for 1.00 CME credits

(Review the [HEART Payment Playbook](#) for more information on using HEART payments for cultural competency trainings building practice capacity to provide culturally competent care, including through staff training)

RESOURCES

What resources can support these changes?

Here are some examples of next steps towards social needs screening or detailed demographic data collection that may fall under HEART Payments according to the HEART Payment Playbook (Table 8). Through technical assistance our team can support the steps needed to implement the below solutions.

Table 8. Example potential HEART Payment activities from the [HEART Payment Playbook](#) and technical assistance opportunities*

Example uses of HEART payments*	Examples of potential MDPCP technical assistance
Employing a Community Health Worker (CHW) to address identified needs of HEART-qualifying beneficiaries	Provide resources on local CHW training resources for recruitment and support of CHWs
Care manager directly contacts HEART-qualifying beneficiaries for needs assessment and to provide high-intensity care management	Help analyze identified needs and link with community resources
Partnering with a local community-based organization to address unmet social needs	Help identify and engage local CBOs that can provide transportation or food delivery, etc.
Modifying EHR to implement social needs screenings	Informatics support to review options and recommend integrated or external platforms for data collection and review
Building capacity to provide culturally competent care	Help identify trainings that will be appropriate and customized to specific practice needs to ask questions in a sensitive and productive manner
Collecting and analyzing demographic and quality data along with SDOH data	Collaborating to determine which validated surveys would be most useful and how to set up an audit and feedback system

* Please review the HEART Payment Playbook and consult with your MDPCP Practice Coach for further details on the HEART payment



MDPCP Technical Assistance Resources Available: Other Example Technical Assistance Opportunities through MDPCP

- Tailored training references on how to use social needs and demographic data
- Co-development of protocols for social needs or demographic data collection based on individual clinic priorities, resources, and needs.
- Assistance in mapping social services relevant for the geographic location and creating print materials for clinics to provide to patients with an identified need
- Informatics/technical support for integrating social needs screening or demographic data collection workflows within your EHR
- Webinars with subject matter experts on commonly encountered barriers and potential solutions
- 1:1 or group consultations to address encountered challenges

FREQUENTLY ASKED QUESTIONS

How much extra time will it take to screen patients for social needs and provide referrals?

While we know your time with patients is very limited, many studies have shown that social needs screening was not burdensome and providers were happy they had implemented these into workflows.⁶ Studies show the average time to administer a social needs screening via the PRAPARE tool and the AHC tool was 1-9 minutes, depending on the patient needs.

What if I can't address all social needs?

It's important to note that the intent of screening a patient for social needs is not to address all of their social needs directly. Even if you are unable to address a need directly or immediately, research suggests that if a healthcare professional can acknowledge the need and use it to destigmatize the discussion and provide contextual care, this conversation can still build trust and improve the patient-provider relationship.⁵ Still, it is important to state how data is going to be used so that the patient is empowered to make an informed decision about what to share.

Why is collecting patient self-reported demographics important?

Demographic data can be used to assess care quality by ensuring that outcomes do not differ by patient characteristics. It is a critical step towards advancing health equity. For instance, practices could examine whether there are differences in completion of preventative health measures by race/ethnicity or social needs and target efforts to reach out to those patients. Self-reported demographic data can also help your practice create targeted educational materials and quality improvement interventions for specific populations.

Why can't I just document social needs or specific demographic data in a patient's note?

Using standardized categories in the EHR allows for comparison between patients and allows for better aggregate reporting. Additionally, if social needs information is not easily identified in the patient chart then patients may be asked the same sensitive questions again unnecessarily.

I don't want to label my patients and I'd rather learn about their social needs and demographics through conversation. What is wrong with doing that?

Many healthcare workers prefer to learn about patient characteristics through conversations. Screeners can be administered in a conversational format. However, if left completely open-ended, you may not ask about a particular social needs and patients may not raise the issue. Asking standardized questions and letting patients know that all patients complete these questions may build more patient comfort in disclosing sensitive information and allow you to get a complete picture of the patient's social needs without making assumptions.

Is MedStar Health Research Institute (MHRI) part of the MedStar CTO?

While both are part of MedStar Health, they have different leadership and roles within the organization. MHRI leads and supports research and operational work not just within MedStar Health but through external funders. The MHRI team will support all MDPCP practices that request technical assistance regardless of affiliation.

FAQ & ADDITIONAL RESOURCES

How do I request technical assistance?

Please reach out to the MedStar Health Research Institute team at MDPCP.socialneeds@medstar.net or call us at 410-610-3893 with any questions or to request technical assistance.

Existing toolkits and resources

[SIREN \(Social Interventions Research and Evaluation Network\)](#) – SIREN's mission is to provide high quality research to advance efforts to address SDOH in health care settings. In an effort to inform best practices and the financial sustainability of health care-based efforts to address patients' SDOH, SIREN has compiled an extensive repository of tools and resources, including an evidence library of articles, reports, issue briefs, webinars and videos.

[State of the Science on Social Screening in Healthcare Settings](#) – This is a report published in 2022 that summarizes findings on social screenings in five sections: prevalence of screening; an update on the psychometric and pragmatic validity of existing screening tools; patients' perspectives on screening; providers' perspectives on screening; and screening implementation.

[AHRQ Toolkit](#) – The AHRQ toolkit aims to help primary care practices that are thinking about beginning to screen patients for social needs. This toolkit will help practices find resources and information to get started, consider what implementation approaches might work best, and understand how practices can use collected information to address patients' social needs, tailor care to their circumstances, and maximize reimbursement.

[Accountable Health Communities Screening Tool](#), along with evaluations, case studies, lessons learned, and evidence on health outcomes.

[Health Leads Screening Toolkit](#) – The Health Leads toolkit is designed to help clinicians implement a system to screen patients for social determinants of health. The toolkit is based on clinically validated guidelines and includes best practices for screening for social needs, plus a sample screening tool, and a screening questions library.

The American Medical Association maintains a page for the [Commission to End Health Care Disparities](#) that is frequently updated with new articles, emerging evidence, and helpful references.

The Institute of Medicine produced a [report](#) on how to collect race, ethnicity, and language that details the importance of this data in healthcare systems.

[Do Ask, Do Tell](#), a toolkit on sexual orientation and gender identity data collection in clinical settings from The Fenway Institute and the Center for American Progress.

Printouts to normalize discussions about needs:

[Poster in English/Spanish](#) on discussion of social needs

[Provider tips](#) on patient-centered discussions

Provider-oriented [folding card](#) on how to ask about sexual orientation and gender identity

REFERENCES

- 1 Social Determinants of Health. U.S. Department of Health and Human Services. 2022, at <https://health.gov/healthypeople/priority-areas/social-determinants-health>.
- 2 Berkowitz SA, Seligman HK, Meigs JB, Basu S. Food insecurity, healthcare utilization, and high cost: a longitudinal cohort study. *The American Journal of Managed Care* 2018;24:399.
- 3 McQueen A, Li L, Herrick CJ, et al. Social needs, chronic conditions, and health care utilization among medicaid beneficiaries. *Population Health Management* 2021;24:681-90.
- 4 Identifying and Addressing Social Needs in Primary Care Settings. Agency for Healthcare Research and Quality, 2021. (Accessed July 15, 2022, at <https://www.ahrq.gov/evidencenow/tools/social-needs-tool.html>).
- 5 Byhoff E, Gottlieb LM. When There Is Value in Asking: An Argument for Social Risk Screening in Clinical Practice. *Ann Intern Med* 2022.
- 6 De Marchis EH, Brown E, Aceves BA, Loomba V, Molina M, Cartier Y, Wing H, Gottlieb LM. State of the Science on Social Screening in Healthcare Settings. 2022. San Francisco, CA: Social Interventions Research and Evaluation Network
- 7 Measuring sex, gender identity, and sexual orientation: National Academies of Sciences, Engineering, Medicine 2022. Report No.: 0309275105.
- 8 Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status. U.S. Department of Health and Human Services Office of Minority Health, 2018. at <https://minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=53>.